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## **Positive Aspects of Parenting a Deaf Child: Categories of Potential Positive Influence**

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**Amy Szarkowski & Patrick Brice**

### **Abstract**

Hearing parents were interviewed regarding the positive aspects of parenting their deaf children. The parent/child dyads were also observed in interactions and parents were asked to record in a journal their reflections about parenting a deaf child. This information was organized into categories that influenced the degree to which parents reported having positive experiences. A total of 42 categories were derived from the data obtained in the interviews, which were further arranged by the researchers into relevant clusters. The clusters allow readers to better conceptualize the influences on parents that impact their ability to have a positive parenting experience. There were six clusters of potential positive or negative impact on hearing parents of deaf children identified in the present study. These included: Parental Positives (internal); Parental Positives (External); Child Characteristics; Deafness; General Concerns; and Parental Negatives. Recommendations for professionals, which were driven by participant remarks, are included as well.

### **Introduction**

The experiences of deaf children have been studied at length. Their performance in school, their reading levels, and their behavior problems are well known in the field of deafness (Vostanis, Hayes, Du Feu, & Warren, 1997; Liptak & Siple, 1981; Meadow & Trybus, 1979). However, the experience of raising a deaf child has not been studied as extensively. Furthermore, much of the research that presently exists frames parenting in a negative manner, such as dealing with differences in behavior and choosing a method of communication, which is typically presented in the literature as a major stressor for parents (Caldron & Greenberg, 1999).

Deaf children, like all children, have positive attributes as well as negative. Though much research in the field of psychology has often begun by identifying and labeling the "abnormal," the deviates from the norm, a new movement is afoot in the psychological sciences (Seligman & Csikszentmihalyi, 2000). The focus has shifted from determining and defining the deviates to searching for and using information about the positive aspects of a given experience.

Using this ideology, the present study considered the positive aspects of parenting a deaf child. The premise of the study was that deaf children have much to offer their parents, despite the difficulties that also arise when parenting a child with special needs. When given the opportunity to describe and explain the positive aspects of parenting a deaf child, parents were able to identify uniquely positive aspects of their situation that would not be in place had their child not been deaf. The potential benefit of this type of research lay in its value to provide hope to parents, to encourage parents to discuss and consider the positives involved with their parenting experience, and to reframe deafness and the deaf experience for those individuals who believe that “disability” equals tragedy. Professionals working with deaf children may also benefit from learning of the positive experiences of parents, so that they might be able to share that information with parents of newly diagnosed deaf children. This has the potential to provide a more balanced perspective than is traditionally given when parents learn the “bad news” that their child is deaf.

#### Parenting Stresses and Deaf Children

Parental stress is thought to mediate the perception of the parenting experience (Meadow-Orlans, 1994). Families with exceptional children, whether the child is physically handicapped or cognitively impaired, face stressors that are not usually considered by parents of typically developing children, at least not to the same degree (Koester & Meadow-Orlans, 1996; Friedrich, Cohen, & Wiltner, 1987). The stresses of raising a special-needs child tend to be chronic and require continual adaptation.

Studies of hearing parents of deaf children typically focus on the additional stressors of the situation and the potential negative impacts that raising a deaf child may have on a family (Calderon & Greenberg, 1999; Brand & Coetzer, 1994; Desselle, 1994; Calderon & Greenberg, 1993; Meadow & Trybus, 1979). Traditionally, children who are born deaf are thought to be “normal and healthy” when they are born, and parents tend to establish goals for their child without knowledge of the child’s deafness (Diefendorf, 1999; Kampfe, 1989). Since the diagnosis of deafness is often initially confused with mental retardation and autism, the reactions to this diagnosis are often strong and profound (Meadow-Orlans, 1994). Other commonly reported reactions to the identification of deafness include anger, self-pity, confusion, and guilt (Greenberg & Kuche, 1993).

Deaf children may be at a greater risk for developing behavior and conduct problems, which can contribute to elevated levels of stress in hearing parents (Henggeler, Watson, Whelan, & Malone, 1990; Greenberg & Kusche, 1989). Additionally, behavior problems are much higher in deaf children whose etiology of deafness is unknown, compared to those with known etiologies, possibly suggesting other confounds that contribute to the behavior problems. Behavior problems add additional stressors in raising children (Schnittiger & Horshoren, 1981; Hirshoren & Schnittjer, 1979). Research has looked at the role of communication in families with deaf children (Kluwin & Gaustad, 1994; Bodner-Johnson, 1991), as well as family dynamics in families with deaf children (Henggeler et al., 1990). These researchers found that parents of deaf children often do not communicate well with their child (many times not even using the same language), and that family dynamics in these families tend to be altered when a child has special needs.

The cognitive and social skills of deaf children can also be adversely impacted by the parents' negative view of deafness (Calderon, Greenberg, & Kusche, 1991; Watson, Henggeler, & Whelan, 1990). Based on work by Friedrich, Cohen and Wiltner (1987), hearing parents of deaf children tend to experience greater isolation, victimization, and self-blame, due to a lack of support from other parents in similar situations. Since the majority of deaf children are born to hearing parents, those parents are often not aware of Deaf culture prior to their child's birth. Since deafness is a relatively low incidence phenomenon in much of the country, parents may have no model on which to base their child's behavior or progress.

### Positive Aspects of Parenting Typically Developing and Exceptional Children

In typically developing children, stresses are usually balanced with the positive aspects of child rearing. Children and adults form attachments that create a bond (Friedrich, Cohen, & Wiltner, 1987). These bonds enable the parent to form and maintain positive feelings toward the child, despite the challenges that raising that child may pose. Webster-Stratton and Spitz (1996) and Lazarus and Folkman (1984) suggest that raising children with special needs has rewards as well. These may include a close family network or a strong bond because of parental concerns about the child. Both young children and adult children with mental illness have been found to contribute positively to their families (Greenberg, Greenley, & Benedict, 1994). In a study by Greenberg et al. (1994) on the contributions of mentally ill persons to

their families, the authors indicated that their research was done in an effort to offset the often-held views that families with “special” children experience only burden. They argued that recognition of the positive roles that persons with mental illness can play in the family and the community is crucial, and understanding those roles may aid in the acceptance of these individuals in their families and reduce the stigma associated with having a special-needs child. In each of these studies of the effects of parenting a handicapped child, deaf children are often not included because of communication barriers in the testing process (Henggeler et al., 1990). Despite the efforts of researchers to learn from parents of deaf children, little focus has been on their positive experiences. However, studies have been completed with parents of mentally ill children, whose circumstances have been compared with those of parents of deaf children because of the aspects of chronic stress (Johnson, 2000). In his qualitative study of the experiences of families with mentally ill family members, Johnson found that parents were able to identify unique and positive contributions of their special-needs child. Similar acknowledgement of the contributions of a deaf child to the family may result in positive outcomes for both the child and the parents.

### Positive Aspects of Raising a Deaf Child

To date, one study has been conducted that considers the positive impact on parents of raising a deaf child. Szarkowski (2000) asked parents of typically developing, autistic, and deaf children to identify their positive experiences with parenting their children. The positive aspects given by parents of deaf children are different from those reported by parents of typically developing or autistic children. Specifically, parents of deaf children reported positive aspects in the areas of communication, Deaf community, and religion. Parents indicated that the access they had gained to American Sign Language was very positive. Many of them had learned ASL and began working with deaf children. The parents also appreciated the efforts the Deaf Community had taken to be involved with their child’s life, and they were thankful for the resources and support available to them. Many of the parents in that study indicated that their belief and/or faith had been challenged by having a deaf child. Some parents felt that their child was a “gift from God” that was sent to teach them lessons, others felt that they had not been a good person, and that having a deaf child was the way they were being challenged to become a better person.

## Methodology

### Research Design

The present study used a methodology typical of qualitative research. Information was obtained via demographic questionnaires, interviews, observations, and reviewing of documents. Data collection was limited to approximately two hours of interviewing and two hours of observation with each family. The parents were interviewed, and the parent/child interactions were observed on one occasion. The parent/child teams were observed an additional time and in a different context, at which time the researcher met with the parent to allow for the parent to add any further thoughts that had emerged since the first visit. Additionally, parents provided feedback that the data obtained was an accurate representation of the perspective of the parents. Finally, the researcher reviewed a journal document that each parent had completed regarding his/her reflections on the positive parenting experiences he/she had during a two-week period.

### Participants

Hearing parents of deaf children were selected because their experiences were likely to differ from those of deaf parents of deaf children. Since 90% of deaf children are born to hearing parents, the results of this study may be more applicable to those families (Meadow & Trybus, 1979). The criteria for participation in the study included:

#### Parents:

1. No significant known hearing loss
2. Could have more than one child with a hearing loss, but were asked to limit responses to their interactions with only one of the children
3. Needed to be willing to complete all three aspects of the present study, including the interview, two observations of them with their child, and a record of their daily thoughts regarding parenting this child (for 2 weeks)

#### Children:

1. Were required to have a 70 dB hearing loss or greater
2. Needed to be prelingually deafened
3. Were between the ages of 1-14 years

**Table 1.**  
Participant Background Information\*

Parent	Race	P Age	C Age	Years of Education	Communication	Assist	Economic Class
Mother	C	50	12	16	Oral/ASL	Aids	Upper Middle
Father	C	50	12	18	Oral/SE	Aids	Upper Middle
Mother	J	40	1	20	ASL/Cue	Aids	Middle
Father	J	40	1	20	ASL	Aids	Middle
Mother	H	20	5	12	Oral	CI	Upper
Mother	C	40	6	19	ASL/TC/Cue	None	Upper Middle
Mother	C	30	3	12	Oral	CI	Middle
Mother	C	20	2	14	ASL/Oral	CI	Lower
Mother	C	40	12	16	ASL/SE	Aids	Lower
Father	J	40	12	12	ASL/SE	Aids	Lower
Mother	J	40	14	16	Oral	CI	Upper Middle

\*Key: Race/Ethnicity: C = Caucasian, J = Jewish, H = Hispanic

P Age = Parent Age Range (decade)

C Age = Child age in years

Education = Number of years of education

Communication: ASL = American Sign Language

Cue = Cued Speech

O = Spoken English

SE = Signed English

TC = Total Communication

Assist (Assistive Devices): Aids = Hearing Aids

CI = Cochlear Implants

Participants were selectively chosen so as to include deaf children and their families from a variety of communication backgrounds in an attempt to be more inclusive of the many ways that currently exist to “be deaf.” Purposive sampling selection is often used in developing an emergent theory, or in establishing maximum variance within a group (Mertens, 1998). The communication modes included sign language, oral communication, cued speech, total communication, and Signed Exact English (SEE). The participants were chosen from a group of 44 parents that inquired about study participation.

The sample consisted of seven mothers and three fathers. The parents self-identified as Caucasian, Jewish, and Hispanic. The children of the parents ranged in age from 1 – 14 years in age. The method of communication used by the parents in interacting with their child was difficult to label, as the majority of parents indicated that they used multiple methods. The methods indicated in the chart above list the current communication method of the parent/child dyads. Many parents indicated that they used various methods depending on the situation, such as using ASL to communicate at home, Cued Speech to teach reading, Oral methods when the child has the cochlear implant on, and Signed English when the implant is not attached. Collectively, six parents reported using Oral methods, seven used ASL, and three reported using Signed English. Two of the 10 parents used Cued Speech to communicate with their child, while one parent endorsed the use of Total Communication.

The range of age of the parents was 20-50, with six parents being in their 40s, while the age of the children of these parents ranged from 1-14 years. The parents were highly educated. Of the 10 participants, three had completed 12 years of schooling, and one had completed 14 years and had obtained an Associate’s Degree. Three parents were college graduates with 16 years of education, while one had completed 18 and another 19 years of schooling. Two individuals had completed 20 years of schooling and had earned advanced degrees.

### The Interview

Hearing parents of a deaf child were asked the following questions:

1. Tell me about what it is like to be a parent of a deaf child.
2. What do you think might be unique to your situation of raising a deaf child that you think parents of hearing children may not experience?



3. What are the most positive things about raising a deaf child?
4. Have your views on raising a deaf child changed since your child was first diagnosed? If so, how?
5. What do you think would be beneficial for other parents of deaf children to know?
6. How has your parenting changed with all your children and what influenced those changes?
7. How do you see yourself parenting in relation to how you were parented? Are you very similar to your parent(s) or very different? How and why?
8. How might you have felt about your situation if it had happened to you at a different time in your life (i.e., you had children much earlier or much later, or when you lived in a different place)?
9. What factors contribute to or detract from your ability to have a positive parenting experience with your deaf child?
10. If the deaf child has siblings, how does having one deaf child impact the other children? How does it influence the sibling relationship?
11. What have I not asked about that you would like to share with me?
12. What other questions would be beneficial to ask in order to learn more about the positive experiences of parenting a deaf child?

The interviews were conducted by the researcher and took place inside the participant's homes, their yards, or in parks near their homes. The interviews were audiotaped, transcribed by the researcher, and analyzed for their content. The use of multiple methods (interview, observation, and document review) were analyzed for content in such a way that recurrent themes emerged. This provided stronger evidence for the presence of certain perspectives and increased the credibility of the study (Strauss and Corbin, 1998).

### Observations

The researcher primarily served as a distant observer (Mertens, 1998) and did not participate in, nor interrupt the parent/child interaction.

The following items were noted during the parent/child observations:

- Physical setting
- Participants (who was there, how they interacted, the ways in which they communicated)
- Activities (including any familial/cultural/ethnic norms that may have been impacting their behaviors)
- Potential impacts of the presence of the researcher

The researcher also made a sketch of the room and the items in the room to better show the interaction that took place. These sketches show the movement of the parent/child pair in the room, indicate important environmental stimuli, and aid in the description of the observation session.

### Document Review

Participating parents kept a journal of their reflections on parenting and were asked to consider three things:

1. Positive experiences that happened during the week
2. The child's recent developmental changes
3. Any noticeable patterns that had developed in their interactions with their child

A notebook was provided to the parent for the journal exercise. Parents were asked to write approximately one page daily for the course of two weeks. For parents who found that journaling was difficult, or who were somewhat resistant to the idea of keeping a journal, email communication was encouraged.

### Data Analysis

Data was analyzed using a comparative method based on Grounded Theory, an iterative process that involves finding commonalities within participant data collection methods and across participants. This method allows for the development of categories, until enough evidence is compiled to lead to the conceptualization of a hypothesis (Merriam, 1998). Because the theory is data driven, no specific hypotheses are suggested prior to the initiation of the research.

This process allowed for the development of potential categories until enough information was compiled to lead to hypotheses. Eisener (1997) identified this as one of the strengths of qualitative research, since hypotheses are data driven.

The following strategies, suggested by Merriam (1998) were incorporated into the research to help ensure the accuracy of the obtained data:

1. Triangulation (obtaining data from multiple methods, looking for emergent themes)
2. Member checks (establishing a feedback loop with the participants, ensuring that their perspectives are being accurately represented)
3. Peer debriefing (researcher meets with a non-involved person who can provide feedback and suggestions on the researcher's initial coding and categorization of participant responses)
4. Progressive subjectivity (acknowledging one's biases and taking responsibility for how those biases might influence the data by taking notes immediately following interactions with participants)

The questions involved in the development of the present research project included:

- Are parents of deaf children able to report positive experiences in raising their child?
- If yes, what are the kinds of positive experiences do they report?

Since the families involved in this project were able to identify positives, this led the researchers to ask the following questions:

- Why did some families easily identify the positives?
- How can professionals working in the field of deafness facilitate positive experiences in hearing parents of deaf children?

### Findings

Forty-two categories emerged from the transcripts of the interviews (see Table 2). These categories are believed to be areas that

directly impact the ability of the parent to have a positive parenting experience. A total of six clusters were derived based on the categories.

**Table 2.** Categories and clusters of Interview Responses.

Parental Positives (Internal)	Parental Negatives	Deafness
Advocate	Detract from a	Deaf Culture
Builds character	positive experience	Deaf role models
Everyday positives	Family difficulties	Deaf siblings
Greater involvement	Move for services	Deafness defined
Highs	Need for unbiased	Sign language
Knowing the child	information	
Letting go	Opinions varied	
Personal growth	Overprotective	
Perspective implants	Statements made in	
Positives	public	
Process of learning	Worry more	
screening	Work changes	
Take for granted		

  

Parental Positives (External)	Child Characteristics	General
Family support	Great kid	1 <sup>st</sup> Reaction
Good time in life	Kid first, then deaf	1 <sup>st</sup> Reaction 2 <sup>nd</sup> time
Location		Cochlear
Support people		Education
Work changes		Hearing
		Advice for parents

The two Parental Positives clusters provide information that has been missing from the literature to date, describing the positive aspects of parenting a deaf child. Parental positives have been divided into two clusters, internal and external. The internal cluster denotes attitudes and perspectives adopted by parents that allow them to view their parenting situations in a positive light. The external cluster identifies many of the resources and environmental pieces that, when in place, can lead to a more positive experience in parenting a deaf child.

Parental Negatives were identified by each parent as well. Parents who have a positive parenting experience are not devoid of having negative experiences with their deaf children. Parents acknowledged the difficulties inherent in raising a deaf child. The frequency of these negatives and the relative impact each has on the parent appear to inversely impact the positive experiences of raising a deaf child. The parents identified aspects to parenting a deaf child that parents of hearing children may not experience.

Child Characteristics include the statements made by parents that deal with their child's temperament and attitude. All 10 of the parents gave their child credit for being "a wonderful child," aside from being a deaf child. Many parents indicated a belief that the child was responsible for the "positive parenting" because of the unique traits of their child.

Lastly, two categories, labeled Deafness and General, dealt with information that did not necessarily have either a positive or a negative impact on parenting perspectives, though they certainly impacted the parents in some way. An example of this might be education, where some parents suggested that the educational system helped them to find the resources needed. Others stated that the educational system was the most frustrating aspect of obtaining the necessary resources needed for their child. Each of the categories within these latter two clusters can be viewed as either positive or negative, dependent upon every parent's unique experience. The parents in the present study offered several suggestions for improvement of these services for other deaf children.

### Categories

#### Parental Positives (Internal)

- *Advocate.* Becoming an advocate for their child was an empowering experience; it made parents feel closer to their child and more involved in the child's life.
- *Everyday Positives.* Those incidents that occur daily in raising a child that are positive, such as seeing the child interact with other children, or watching as they learn something.  
 "All the things he does each day seem like a miracle to me. When he wakes up and signs to me, 'Good morning, Mommy' I feel such pride in looking at this child. The things he does everyday are the positives, what keeps me going."
- *Greater Involvement.* The level of involvement they have with their child is significantly greater than they might have had with a typically developing child. While admitting this can be demanding,

most parents suggested that this greater level of involvement with their child was one of the true assets of parenting a deaf child.

- *Highs.* Nine of the ten parents involved in the present study used the word “high” to describe how they felt when their deaf child achieved or succeeded.

“It’s like...when things happen that are good, and we see progress in her, it’s better than if she were hearing and developing normally. It’s like the joy that you get, the highs, they are off the scale.”

- *Knowing the Child.* Parents indicated that they believed they really knew their child, and attributed that in part to the fact that their child was deaf.
- *Letting go.* When a child has special needs, parents are more likely to be overprotective of them. However, some parents identified the act of “letting go” as positive for them.
- *Personal Growth.* Challenging times, such as dealing with the new diagnosis of deafness in one’s child, can be difficult. Yet, these events, in the words of the parents, “make you grow.” Every parent involved in the present study identified personal growth as one of the positives that have resulted from parenting a child who is deaf.

“Getting stronger as a person, for me it’s like, ‘If I can do this, I can do anything.’ I view myself differently than I did before, in a much more positive way.”

- *Perspective.* With the initial diagnosis of deafness, many parents report feeling “it is awful, the worst thing that can happen.” As parents become accustomed to this diagnosis, their perspective of what deafness is, and what it means to raise a deaf child, frequently changes.
- *Positives.* Parents indicated that raising their deaf child is a positive, wonderful experience for them. Despite the potential difficulties in raising a deaf child, the majority of parents would not want to change their situation if given the opportunity.

“Parents need to know that this can be such a wonderful thing.

It’s not as bad as people make it out to be. In fact, if you asked me if I wanted to change it, I would say, “NO WAY!”

- *Process of Learning.* Since deaf children are not automatically exposed to language in the same way hearing children are, it can be difficult to teach language skills. Parents expressed amazement at the way children learn and the complex learning that takes place in their children.

- *Take for Granted.* One of the most common comments made by parents was the fact that so much of raising a child is taken for granted. Raising a deaf child often increases the awareness of things that were previously taken for granted. Parents reported that “taking less for granted” was one of the remarkable benefits of having a deaf child.

#### Parental Positives (External)

- *Family Support.* Having a supportive partner or spouse and extended family was viewed as critical for many parents raising deaf children. When it is available, additional support seems to lessen the impact of stressors associated with parenting a deaf child.
- *Good time in life.* Despite the differences in age of the parents in the study and the various times in their lives in which they had a deaf child, every parent reported that the child was born at a “good time in their life.”
- *Location.* Living in the greater Washington, D.C. area allows for more access to deaf-related services than most other places in the United States. Parents acknowledged that having these services was beneficial to their parenting experience. Access to deaf individuals, professionals trained in deafness, and educational opportunities for deaf children were all important factors in either determining location for some families, or appreciating location for others.
- *Move for services.* Families had moved for services, or were considering moving to areas they perceived as more “deaf friendly.” These were considered positive external characteristics because parents viewed the services as important and beneficial. While there are certain stressors related to moving for services, parents indicated that they appreciated that services were available and would do what they could to get the services that their child needed.
- *Support People.* Parents that participated in support groups with other parents reported the substantial assistance they received. Many parents indicated that this was the most important action they took in their child’s early life, when they themselves were first dealing with the diagnosis and determining what courses of action to take in meeting the needs of their child.  
 “Then we met the group, and that was great. I wouldn’t have wanted to go through this without them. They have been so much support. I’ve made good friends, and have people who understand what I am going through. There are good things

about all things, definitely. The parent's group is definitely one of the good things about having a deaf child. They were great."

- *Work Changes.* As a result of the additional appointments required by many deaf children to audiologists, speech and language pathologists, and doctors, a majority of parents opted to change their work schedules or careers. Parents stated that these changes were beneficial to them.

#### Parental Negatives

- *Detract from a positive experience.* Although all of the parents of deaf children could identify and discuss their positive experiences, they also experienced situations that detracted from having a positive parenting experience.

"With a hearing baby you don't have to go to the doctor as often. That's because it's not just the doctor, it is also the audiologist, the hearing specialist, oral teachers, sign language teachers...you get the picture."

- *Family Difficulties.* Family support was identified as a positive aspect. When that support is not present, parents of deaf children find parenting more difficult, even stressful. When extended family do not attempt to understand issues related to deafness, it can isolate parents of deaf children and make it difficult for the child to relate to their relatives.
- *Move for services.* Though many parents reported being happy that they moved for services, others cited drawbacks as well.
- *Need for Unbiased Information.* Parents had very strong reactions when asked about the information they received when they first learned of their child's diagnosis, expressing frustration that the information sources with whom they spoke and interacted had such strong biases.

"Later I could research on my own, but in the beginning it just felt too overwhelming to do that. I didn't know where to start. I wanted someone to talk to me without a biased opinion from one of the strong 'camps' on how to raise a deaf child."

- *Opinions Varied.* Parents of deaf children struggled with wanting to do "the best thing" for their child. Yet, they found it difficult to determine what the best thing might be because the opinions varied so greatly depending on the individuals or groups consulted.
- *Overprotective.* Parents in the present study reported feeling more protective of their deaf child than they did of their other children. They saw this as a negative, as something they hoped to overcome.



- *Statements made in public.* Parents reported being confronted in the community about the way they raise their child. Although the comments they received were mixed, very judgmental and very supportive, parents seemed to resent that individuals they did not know were making judgments about them as parents, in a way they might not if their child were hearing.  
 “Sometimes it’s very frustrating because people speak their minds without really knowing what they are talking about. I’m pregnant with my second child, and recently I had a woman ask me, ‘Why would you do that?’ I said, ‘Do what?’ She said, ‘Why would you bring another deaf child into this world? That is the meanest thing I think I have ever heard of. The world doesn’t need more poor people like her (pointing to the deaf child) to take care of.’”
- *Worry more.* Since special needs children have a tendency to be picked on, parents reported a lot of concern about the welfare of their child.
- *Work Changes.* Though many parents reported positive repercussions associated with work changes, other parents found it difficult to change jobs in order to provide more care for their deaf child.

### Child Characteristics

- *Great kid.* Parents praised their children for their skills and attributes. It is difficult to know the extent to which the child’s attitudes and disposition are related to their circumstances, the role modeling they receive, or their genetics. Regardless, parents stated that their child was simply a “great kid” and reported that as one of the benefits of raising their particular child.  
 “He is funny, comical, and delightful. I don’t know how different he would be if he could hear, but I wouldn’t want to find out. He is simply a great kid, and I am proud to be his mother.”
- *Kids first, then deaf.* Every parent in the present study made comments about their child being a child first and foremost. The fact that their children are deaf was secondary to these parents, and they reported that they wished it were secondary to others as well.  
 “I have happy, healthy, normal kids. Other people, and sometimes me too, can forget that. I have two children that happen to be deaf. They are children first.”

### Deafness

- *Deafness Defined.* Parents seemed to struggle with the definition of deafness and what it means in terms of their lives, with their children.

“And then there is that label of deafness, it is hard to know what that means. It’s not a black and white issue. I know with my son, he was labeled severely to profoundly deaf. Yet, with his hearing aids he can respond to oral speech quite a bit. He listens auditorily and is also oral. He talks quite a bit actually. So, well, I know that he is deaf. Without his hearing aids he can’t hear anything. But he is very functional, and so it’s hard to know what the definition of deaf really is.”
- *Deaf Culture.* Parents that have opted to raise their children using ASL indicated that being a part of Deaf Culture was an important aspect to being deaf. They viewed this culture as an additional opportunity for their children.
- *Deaf Role Models.* Exposing deaf children to other deaf individuals, especially adults who are successful in their careers, was important for many parents.
- *Deaf Siblings.* In this present study, three of the ten parents involved had two or more children with hearing loss. They described the sibling relationship as very positive.

“I have thought about this before, like if one of them was deaf and the other had perfect hearing. I think I might give more attention to the deaf child. This way, my attention goes to both of them, and they both get a lot of individual attention and care from me.”
- *Sign Language.* Many parents opted to try communicating with their children using ASL at some point. Some have continued to use this method, while others found it difficult and confusing for their children.

### General Comments

- *1<sup>st</sup> reaction.* Parents reported that learning of the diagnosis of hearing loss was difficult for them initially. Before they learned that their children could not hear, many parents were unaware of deafness, Deaf Culture, or communication methods until confronted with these issues.
- *1<sup>st</sup> reaction, 2<sup>nd</sup> time.* Since three parents shared the experience of having two or more children with hearing loss, they were asked how their reactions differed the second time. Interestingly, parents

reported that learning of the diagnosis the second time was more difficult.

- *Education.* Questions concerning the “correct” or “appropriate” way to educate their deaf children were of great concern to parents. This issue is faced by parents regardless of which communication method they choose to use with their child.
- *Hearing screening.* Parents suggested that hearing screenings be done on every newborn. They expressed frustration that this is not the current practice in many places.
- *Advice for parents.* Having been through difficult times, adjustments, joys, and accomplishments with their deaf children, parents were eager to share their “wisdom” with other parents. The majority of parents continue to be involved with parenting groups and many of them are now leaders within these circles. They expressed a sincere desire to assist other parents and welcomed this forum, by participating in the present study, to discuss their ideas about what parents of deaf children should know.

“I think that parents need to know that every child is unique. Having a deaf child is an opportunity to be exposed to things that, without him, you would never experience. Enjoy it!”

### Conclusions & Recommendations

The categories that emerged from the interviews with the participants indicate that hearing parents of deaf children report positive experiences in raising their deaf children. A total of 42 categories were derived from the data obtained in interviews of hearing parents of deaf children. These categories were arranged by the researchers into relevant clusters, which allow readers to better conceptualize the influences on parents that impact their ability to have a positive parenting experience. This resulted in 6 clusters of potential positive or negative impact on hearing parents of deaf children. These included: Parental Positives (internal); Parental Positives (External); Child Characteristics; Deafness; General Concerns; and Parental Negatives. The first three categories listed above appear to facilitate the potential for parents to report having a positive parenting experience with their child. These areas help to provide a glimpse into their experience for the professionals working with them, and provide a guideline in addressing specific areas of concern. The next two categories, Deafness and General Concerns, were listed by some parents as positive, others as negative. The interpretations, for example, of the influence of Deaf Culture or the

educational system for deaf children were neither inherently positive nor negative, and varied by the individual experiences of the parent participants in the present study. These factors, however, were mentioned by the vast majority of the parents, who stated that the impact of these situations was significant, whether positive or negative for each parent. It would seem a logical conclusion, then, that improvements made in these areas, where applicable, could have a significant positive impact on parents. The last category, Parental Negatives, included many of the concerns and difficulties faced by hearing parents of deaf children that would not typically be of concern with parents of typically developing children, such as the need to move for services, the difficulties in making major decisions based on a variety of mixed opinions, and the challenges involved in “protecting” one’s deaf child while simultaneously striving to not be overprotective. The frustration voiced by parents in the present study closely echoes those of parents in a larger study with hundreds of parent participants completed by Mertens, Sass-Lehrer, and Scott-Olson (2000).

### Recommendations for Professionals

The following list of suggestions was derived from the input of the hearing parents, who shared their difficult experiences of working with professionals and provided their input on possible ways in which to improve interactions between professionals working in the field of deafness and the parents who they serve. They are suggested by existing data, though organized and interpreted by the researchers.

1. *Unbiased Information.* The single most common complaint of parents was the biased information that they received from professionals. Parents reported that they did not receive adequate information about all of their choices because of the biases of the professionals they encountered. Professionals need to consider their own biases in working with families with deaf children and be able to acknowledge them. Professionals should educate themselves regarding the various concerns and decisions faced by parents of deaf children and be able to discuss with the parents their views on the various topics. Information that is provided in the form of handouts and brochures should be balanced and informative.
2. *Listen to the parents.* Often, parents do not know what questions to ask. Parents complained that when the professional says, “That is all I have to say, do you have any questions?” they feel overwhelmed. If the parent has a newly diagnosed deaf child, it is likely that the

parent knows very little about deafness. However, by asking the parents to address their fears, their expectations, or to simply share their concerns about their child, the professional will develop a better understanding of that parent and what that parent might need. Parents should not be treated as though they know nothing, despite their relative lack of knowledge about deafness. Regardless of the deafness aspect, the parent is aware of the resources, supports, and barriers that are involved in their own lives. By listening, professionals will be able to suggest appropriate interventions.

3. *Give the parent something to do.* Parents of newly diagnosed deaf children reported feeling that they had to “sit back” while these changes happened to them. Help parents to become active in the process, allowing them to feel that their contribution to the “team effort” in treating their child is important. Depending on the educational and motivational levels of the parents involved, it may be appropriate to give them readings or sources to search for information pertaining to deafness. Encourage them to talk with individuals from the “other camps” so that they do not make a decision based solely on the advice of one professional. Parents in the present study all reported that they wanted to be involved in determining the best methods for meeting the needs of their child, though they often did not know how to proceed. Encourage them.
4. *Suggest obtaining external support.* External support was reportedly vital to most parents. Prepare a list of contacts or support group meetings that can be handed to parents at the end of each meeting. Many parents are resistant to entering such a group initially, whether they do not view themselves as having problems or because they fear involvement in such a group. Parents often need to be told that groups exist and be encouraged to become active in them. Parents indicated that involvement in support groups was important in helping them cope with the initial diagnosis. Several of those parents are now leaders in support groups for other parents.
5. *Ask parents about the positives.* Too often, professionals want to fix what is wrong. That is our job. Yet, parents need a venue and an audience to express those aspects that are positive in their experience of raising a deaf child, as much as they need to share their frustrations and concerns. Rather than focusing on how a deaf child is not learning to speak well and addressing the frustrations the parents feel with that scenario, ask the parents about the progress the child has made since the last visit. Parents are proud of their children and want to share their positive experiences. Giving the

opportunity to identify positives in their experiences will assist parents in reframing their experiences. One parent in the present study indicated that she had never thought about the positives, because all of her appointments with doctors, audiologists, etc, focused on the degree of *loss* and the level of *impairment*. This same parent, two weeks later, wrote that asking her to identify positives had changed her way of thinking about her child. She indicated that she began to ask herself everyday about the positives of parenting her deaf child, and found this helpful in relating well with her child.

6. *View the child, not the deafness.* Professionals need to remember that “Deaf children are children first, then they are deaf.” Do not lose sight of the fact that the young deaf person you are working with is someone’s child. This child faces challenges that make him/her unique compared to their peers. Help the child to feel unique and special rather than strange and awkward. Children in this study looked to outsiders for confirmation that they were “OK.” Being deaf certainly impacts many areas of the child’s life, yet the child is not a “subject” to be studied so much as a child to be understood and helped.

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